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ABSTRACT

This conference report summarizes presentations and discussions of a workshop on vocational rehabilitation and behavioral and social sciences research, which was intended to promote exchange of information within the research community, better management and planning within research projects sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), and utilization of research results. The report begins with a foreword by Robert R. Davila stressing the practical effects of research on the lives of people with disabilities, and opening remarks by William H. Graves, the NIDRR Director, discussing NIDRR's seven major goals. The report then explores the enlarged focus of current NIDRR-funded research into the areas of children, families, community integration, and supported employment. Chapter 3 summarizes recommendations developed by discussion groups organized around 10 research and training themes: (1) outcome research, (2) intervention research, (3) research for new and underserved populations, (4) systems change research, (5) research on self-determination and consumer participation, (6) policy research, (7) attitudinal research, (8) research to improve training, (9) multicultural research and training, and (10) technology transfer. Chapter 4 offers reflections on the conference recommendations, by William H. Graves. Appended are group summaries, a list of participants, and an overview of the Rehabilitation Services Administration Program. (DB)

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NIDRR

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

U.S. DEPARTMENT OF EDUCATION

Office of Special Education and Rehabilitative Services

Washington, D.C.

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NATIONAL WORKSHOP ON VOCATIONAL REHABILITATION, BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

CONFERENCE REPORT

Bethesda Marriott Hotel
Bethesda, Maryland

October 30 - November 1, 1990

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NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

UNITED STATES DEPARTMENT OF EDUCATION

NATIONAL WORKSHOP ON VOCATIONAL REHABILITATION, BEHAVIORAL, AND SOCIAL SCIENCES RESEARCH

BETHESDA MARRIOTT HOTEL
BETHESDA, MARYLAND

OCTOBER 31 - NOVEMBER 1, 1990

REPORT ON PROCEEDINGS

PREPARED BY

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National Workshop on Vocational Rehabilitation, Behavioral, and Social Sciences Research/Conference Report

October 30 - November 1, 1990

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INTRODUCTION

The purposes of the National Workshop on Vocational Rehabilitation, Behavioral and Social Sciences Research were:

1. To promote the exchange of information and ideas within the research community while, at the same time, assisting NIDRR in its monitoring responsibilities;

2. To promote better management and planning within NIDRR-sponsored research projects by involving research leaders in the long-range planning process of NIDRR; and

3. To promote the utilization of research results by involving directors of NIDRR projects in the selection of appropriate topics for consensus conferences.

The objectives of the small group discussions were:

1. To identify the major issues and populations served by the discussants:

   - o What disabilities were represented by group members?
   - o What should the major outcomes of research be for children and adults with disabilities?

2. To identify major research questions that are currently being asked by researchers, people with disabilities and their families, service providers, and policy makers;

3. To identify state-of-the-art research now being conducted. Responses to this objective should reflect the research now being carried out by NIDRR grantees as well as other major research efforts;

4. To identify the way in which research can assist in developing supports and services that will enable all people with disabilities to participate fully in community life.

Throughout the discussions which took place at the National Workshop on Vocational Rehabilitation, Behavioral, and Social Sciences Research, a common understanding of underlying values appeared in each presentation and throughout the group discussions and responses. They included the following:

- Each infant, child, adolescent, and adult with a disability has a right to respect and to equality. This should be reflected in every rehabilitation research design.

- The purpose of research is to promote full community membership and equality for people with disabilities.

- Each person with a disability makes positive contributions to his/her family, friends, and community. Research designs should identify and build on the strengths of people with disabilities.

- Most people with disabilities have a family network to which they belong. Continued research is needed on best ways to integrate and support family members into the person's rehabilitation plan.

- There are people in every culture who are born with or acquire disabilities in their lifetime. Persons in rehabilitation research, training, and service delivery must recognize this fact and design their research and services in ways that are reflective of cultural mores, religious beliefs, ethnic differences, language groups, gender, and age differences.

- It is important to recruit and train staff from all cultural and ethnic groups so that people with disabilities from those groups may receive appropriate services. If it is not possible to recruit such staff, the participating staff members must receive training so that they are sensitive to the unique aspects of the various cultural and ethnic groups.

- New populations of people with disabilities are emerging in the 1990s. These include people with traumatic brain injury and persons who are HIV positive. It is important that rehabilitation research and training be carried out concerning appropriate ways to serve these populations.

- Rehabilitation research should be carried out across the life span of people with disabilities so that appropriate supports and resources can be developed and provided when needed.

- People with disabilities have the right to assist researchers in conceptualizing, designing, implementing, and evaluating research and in providing feedback relative to outcomes.

- There is a need for a continuing emphasis on research that will enable consumers to achieve self-determination and full empowerment.

- Each person with a disability has the right to live, go to school, work, and play in the community. Continuing research is needed to determine the best ways to support and provide resources for each consumer in the community of his/her choice.

- In order for research to have maximum positive impact, it is essential that preliminary, as well as final, findings be widely disseminated to the consumer, their service providers, and Federal, state, and local legislative and regulatory bodies.

- It is important for research to validate ways in which to support and strengthen the family, friends, neighbors, and other persons who are mainstays in the lives of children and adults with disabilities.

- Rehabilitation research, training, and service delivery should encompass activities that promote the social integration, productivity, and independence of children and adults with disabilities.

L. Deno Reed, Sc.D.
Sylvia Walker, Ed.D.

FOREWORD

REMARKS OF ROBERT R. DAVILA, Ph.D.

Assistant Secretary for Special Education and
Rehabilitative Services
U.S. Department of Education

FOREWORD

It is a real pleasure to be here today. I appreciate the opportunity to meet with such a diverse group of NIDRR project directors. I almost feel as though I am still in the Switzer Building. Everything the Office of Social Education and Rehabilitative Services (OSERS) stands for is represented right here in this room. Your agenda says you are focusing on family members with disabilities, education issues, preparation of persons with varying disabilities for life in the community, vocational rehabilitation, supported employment -- what a challenge! Only a group this talented could meet it.

This kind of meeting is a wonderful idea. I am a firm believer in "Family Reunions." And, just like at those old-fashioned gatherings, I can see you swapping recipes -- a pinch of planning know-how, a touch of technology transfer, a dash of dissemination expertise, and before you know it, the information melting pot is bubbling nicely.

I want especially to welcome the newest member of this family; The Research and Training Center for Traditionally Underserved Deaf Persons, at Northern Illinois University. I predict you will leave here having gained a great deal of confidence and encouragement from the oldtimers. That is part of the reason we are here, after all: to learn from each other. I say "we" because the interchange is not just among the grantees and project officers. The advice you give and the suggestions you make regarding future planning, consensus panels, improved monitoring, information dissemination and utilization will be helpful to NIDRR, of course, but I am counting on Bill Graves and Deno Reed to share their wealth with the rest of OSERS, too.

We at the Federal level need this kind of contact. We promulgate policies and create program possibilities and funding mechanisms. But you are the ones who take our work and bring it to life. Without you, all our efforts would produce only so much paper. It is through you that the time and energy which we expend take on real value. I truly believe that everyone in OSERS is dedicated to the goal of improving opportunities for people with disabilities, but from our offices we cannot see how that goal truly is achieved. You make it real for us, and for all you do, we thank and salute you.

It is a source of great encouragement--I might even say inspiration--for me to remember that throughout this nation and even beyond our borders, thousands of intelligent, highly-trained people are sharing the mission which I have established for OSERS: To insure that all individuals with disabilities have the means and the opportunity to achieve their

maximum potential, and that they become fully-participating members of society by pursuing whatever educational or occupational objectives for which they choose to strive. I emphasize that they must have the opportunity to make these choices for themselves.

This mission can be realized only if we adopt and maintain a philosophy that demands total equality for all citizens, regardless of the severity of their disabilities. You obviously agree with that philosophy, or you would not be in this business.

It is good to see that our friends on Capitol Hill are with us too. I am referring, of course, to the landmark passage of the Americans with Disabilities Act (ADA). As efforts to implement that Act proceed over the next few years, I think we will see our hopes and expectations realized in ways never before imagined. As he signed the ADA, President Bush called it "The sledgehammer that will smash the many barriers confronting people with disabilities." An excellent metaphor. Already, disability organizations are looking for ways to wield that hammer most efficiently. That is where you in the research community come in. As you continue your quest for better treatment systems or improved rehabilitation strategies, remember your obligation to reach out and include the disability community. In all of your projects, from original concept to final report, I urge you to adopt what Bill Graves calls "participatory research." This means that persons with disabilities must be more than just the subjects or beneficiaries of your work; they must also be co-planners, co-investigators, co-writers, and project directors. Even those with good records in this regard are encouraged to step up their efforts. In this way, utilization of the knowledge you generate will be more easily disseminated to the people who have the most need to know what you are doing.

Forty-three million Americans with disabilities are watching us. Whether or not they know the names of specific agencies or projects, they know the Federal government is funding a great deal of research that could affect their lives, and they want to know what is going on. All of us, we at the Federal level and you in the field, must give a full accounting of our stewardship whenever it is called for. Let us not be found wanting.

We will not be found wanting if we keep in mind that research simply cannot exist in a vacuum. That research must not be conducted simply to find material for a final report. Along that line, I am reminded of Jonathan Swift's classic Gulliver's Travels. One of the islands Gulliver visited was inhabited by scientists who spent their time deeply pondering weighty problems. They pondered so deeply, in fact, that they often lost touch with a conversation, forgetting even that they were conversing with someone. When that occurred, an assistant would tap the scientists on the head with a balloon and remind them what they had been talking about. I know Dr.

Reed and his staff would gladly tap any project director on the head to get things back on track, but that should never be necessary, and I'm sure it never happens.

One of OSERS' most important responsibilities to you is to define the program funding priorities as completely as possible, so that you can change the world for some people with disabilities. That might seem to be a bit grandiose, but I have seen it happen. When someone with mental retardation goes from watching TV all day to putting in six hours of supported work, that is a world change. When someone who is considered almost totally helpless discovers and meets the challenge of independent living, that too is a world change. I have not read your reports, but I am confident that every project represented here could point to several such successes.

A proverb attributed to the Chinese says that a journey of a thousand miles begins with a single step. America's citizens with disabilities have a long journey yet ahead of them before they reach full equality. The road has been paved, in part at least, by the Rehabilitation Act, the Fair Housing Amendments, and the Americans with Disabilities Act. And you, the NIDRR project grantees, are out there lowering the gradients, gentling the curves, and building bridges.

When I talk with organizations not related to NIDRR or OSERS, I point out that everything done to better the situation of people with disabilities has a positive effect on society as a whole. Therefore, it is in their best interest to work with us, to join our community of concern. A lot of hard work remains to be done, but this nation has frequently demonstrated that pulling together we can be victorious. I like the way President Bush put it at the ADA signing ceremony: "The problems are great, but our united heart is greater."

Thank you for inviting me to be with you today.

Robert R. Davila, Ph.D.

ACKNOWLEDGEMENTS

The conference coordinators would like to extend their warmest and sincere appreciation to the conference participants who contributed to the success of the "National Workshop on Vocational Rehabilitation, Behavioral, and Social Sciences Research" and the publication of this report.

We are especially appreciative of the outstanding contributions which were made by each of the group leaders. Special thanks to Dr. Robert Blum, Dr. Gail McGee, Dr. Robert Bruininks, Dr. Marilyn Johnson, Dr. Joseph B. Moriarty, and Dr. Dale Thomas.

We would like to thank staff members of the Howard University Research and Training Center and of other institutions and organizations who facilitated the accomplishments of the project's goal, providing a stimulating and informative conference in an atmosphere of fellowship and the subsequent publication and dissemination of this conference report.

L. Deno Reed, Sc.D.
Sylvia Walker, Ed.D.

CHAPTER 1

OPENING REMARKS

WILLIAM H. GRAVES, Ed.D.

Director
National Institute on Disability and Rehabilitation Research
U.S. Department of Education

OPENING REMARKS

INTRODUCTION

It is my distinct pleasure and personal privilege to be here with you at the first meeting of Project Directors of the Vocational, Behavioral, and Social Sciences Team of the National Institute on Disability and Rehabilitation Research (NIDRR). I want to add my welcome to Bethesda, Maryland, to those you have received earlier this morning. At this time, I would like to thank Robert R. Davila, Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), for his enthusiastic support of this meeting, as well as his support of the other Project Directors' meetings that have been scheduled by NIDRR this fall. It is important that I also thank Nell Carney, Commissioner of the Rehabilitation Services Administration (RSA), and Judy Schrag, Director, Office of Special Education Programs (OSEP), for their understanding of the need for their interest in and support of this meeting, as well as for their enthusiastic participation in the meeting. The support and attention Dr. Davila, Mrs. Carney, and Dr. Schrag are giving this meeting is indicative of the team approach taken in OSERS. This team approach has enabled each of the OSERS components to make considerable strides this past year in meeting the needs of people with disabilities.

The Project Directors' meeting is an opportunity for the OSERS team to bring another group more fully on the playing field. The Project Directors are 2 that the NIDRR (third of the OSERS Management Team) relies on to accomplish a considerable part of its mission. This group is you, the Project Directors and the fine staffs you have assembled to work on the projects that NIDRR funds. The projects which you direct are at the heart of the NIDRR mission. Your leadership as Project Directors makes the difference for NIDRR and for people with disabilities. Let me assure you that each of us at NIDRR recognize the fact that most of the time you carry the ball while those of us sit, watch, wait to be called in, and then afterwards, maybe even play a little Monday-morning quarterback.

Before I say much more, I want to let you know it is good to see so many members of the Vocational, Behavioral and Social Sciences Team here. You give me confidence that NIDRR will continue to play an important role in empowering people with disabilities. Research, development, and training in this critical area will do much to fulfill the President's vision of the contributions of the Americans with Disabilities Act (ADA) to people with disabilities. I know that through your efforts, the shameful walls of exclusion that President Bush so eloquently described when he signed the ADA Bill on July 26, 1990, will indeed tumble down and become dust to be trampled by men and women in wheelchairs, with leg braces, with white canes, with hearing aids, or other assistive devices.

This is the first Project Directors' Meeting of the NIDRR Vocational, Behavioral, and Social Sciences Team. Project Directors of rehabilitation research and training centers, rehabilitation engineering centers, field-initiated research, research training grants, and interagency agreements whose projects are supervised by Deno Reed, David Esquith, Roseanne Rafferty, and Delores Watkins are here.

CONFERENCE GOALS

There are four goals of the Project Directors' Meeting. The first is enhanced communication. This meeting represents an opportunity for NIDRR to enhance communication and information dissemination about vocational, behavioral, and social sciences for people with disabilities. This meeting is an opportunity to strengthen communication between the Project Director and the Project Officer. I hope each of you will take advantage of the time you have to get to know each of the fine members of the Vocational, Behavioral, and Social Sciences Team better and to assist them to understand your project better. This interaction will afford you an opportunity to acquaint the NIDRR team with the goals of your project and its potential for empowering people with disabilities.

One of the principle types of communication which I hope will occur is linkages and networking between the Project Directors. There are a number of different disciplines represented by the Project Directors attending this meeting. There are scientists from each of the disciplines here today. Each of you and the disciplines you represent view the needs of people with disabilities from different perspectives. Each of you has a different research methodology that contributes uniquely to people with disabilities. Yet, like the OSERS team, each of you has a common mission. The common mission is producing products, strategies, or programs that facilitate the empowerment of people with disabilities. As a result of increased communication among the projects and programs you direct, new answers to the age old problems that cause people with disabilities to be excluded from the mainstream of society may be developed. For example, new ideas and directions might emerge that enable the seven year old boy I met in Arkansas (who has mobility and speech disabilities), to become employed when he graduates from post-secondary school. More importantly, with the contributions of the Vocational, Behavioral, and Social Sciences Team, his rehabilitation counselor will take this young boy's potential for employment as a matter of course rather than as a special placement achievement. I hope that some of you take this opportunity for communication to lay a foundation for future collaboration between Project Directors. Who knows, some of you may communicate so well that you submit a joint proposal to NIDRR that is funded!

If we take full advantage of this opportunity for increased communication, then steps will have been taken to foster a sense of community among disability and rehabilitation researchers. Lewis Thomas in Lives of a Cell describes the inefficiency of a single ant acting alone and contrasts the work of a solitary ant with the efficiency, intelligence, and achievements gained through the colony or community of ants. While I don't want you to assume I think that individuals engaged in disability and rehabilitation research are ants, I do want you to consider the effect that a community of scholars and researchers can have on addressing issues that affect the empowerment of people with disabilities. With an increased sense of community among disability and rehabilitation researchers, greater understanding of issues touching people with disabilities can be achieved.

One other outcome of increased communication that is worthy of comment is the opportunity we have to discuss NIDRR's role within OSERS so that you might understand how the contributions you are making through your projects affect not only NIDRR, but also the Rehabilitation Services Administration and the Office of Special Education Programs. I tell people that NIDRR is the creme filling in a cookie. Like the creme filling, many regard it as the best part. Physically, no doubt, you have noticed on your visits to the Mary Switzer Building and NIDRR that NIDRR is located right in the middle of RSA and OSEP just like the creme filling in a cookie. This location is symbolic in the sense that your work supports and holds together the delivery of services through agencies and projects funded by RSA and OSEP.

A second goal of this meeting is to provide an opportunity for NIDRR project officers to monitor projects first hand. It gives you, the project officers, and me a chance to identify new directions that the project should take, I am sure that in most cases you will stay on the same fine course you are on currently. With increased understanding between the Project Director and the Project Officer, NIDRR can be more helpful in the management of the grants and in answering questions which the Office of Grants and Contracts might have about each project. As a result of the discussions which will occur between the Project Director and the Project Officer, both may identify emerging issues in the field and share their views on these issues with other Project Officers at NIDRR, as well as other researchers in the field. While this new understanding of emerging issues is important, it is equally important that the NIDRR Vocational, Behavioral, and Social Sciences Team have an increased awareness of the state-of-the-art in the field. This knowledge will provide for better assessment of research issues.

A third goal of the meeting is to receive input from NIDRR grantees regarding research needs and opportunities that might be incorporated in the long-range plan of NIDRR. While it was stated in the letter from Howard University that this input would be sought, I want to stress how important this input is to the development and direction of the research activities of the

NIDRR over the next five to seven years. As you may or may not know, the NIDRR is required by law to have a five-year research plan. While the 1981 plan has been updated over the past ten years, a totally new plan has not been developed. The Project Director's Meeting is the first step in the development of the new NIDRR long-range plan. During this meeting, you will have an opportunity to provide input that identifies disability and research needs in your respective disciplines or concentrations. I hope that in the process which will occur over the next day or so, you will give considerable thought to the identification of disability and rehabilitation research needs. These needs should be identified in a climate which is sensitive to the importance that NIDRR places on the development of strategies which facilitate the empowerment of people with disabilities.

As you report disability and rehabilitation research needs, one of the central questions we at NIDRR will be asking is, "Will the research matter be important, or contribute to the empowerment of people with disabilities?" The research program at NIDRR must increasingly be one that facilitate empowerment and self-reliance of people with disabilities and their families. The research programs in vocational, behavioral, and social sciences must be undergirded by empowerment principles. Those needs that are identified must foster self-reliance and collaboration between the researcher and the person with a disability and his or her family. The intent of NIDRR policy will be to identify and invest in research and training priorities that empower persons with disabilities. This policy option complements the rehabilitation philosophy of self-reliance, independence and dignity of the person with the disability.

The strategy to be used by NIDRR in the development of the long-range plan is one that is based on input from many constituent groups and organizations. One of the primary groups from which input is needed includes researchers such as you, who are receiving funding from the NIDRR to engage in disability and rehabilitation research. Your unique input will assist us in taking positive steps toward the identification of research needs based on the work, understanding, and commitment of disability and rehabilitation researchers. Thus, I am looking forward to hearing and receiving input from you regarding the future direction which NIDRR should take in all of its programs, including vocational, behavioral, and social sciences.

This activity is the first step in the long-range planning process. An announcement will appear in the Federal Register within the next few weeks relative to a public hearing on the NIDRR long-range plan. The purpose of the hearing, which will be held in Washington, DC, is to receive public comments on disability and rehabilitation research needs that might be addressed by NIDRR in the next five to seven years. The November, 1990 hearing will be followed by regional hearings which will be held in four to six cities across the United States. The dates and places of these hearings will

also be announced in the Federal Register. As these regional hearings are being conducted, papers will be commissioned pertaining to issues identified in the Project Directors' meetings and in the Washington public hearing. If additional issues are identified in the regional hearings, additional papers will be commissioned. The National Council on Disability will also be holding a hearing and developing a paper to examine specific research needs in this field as perceived by individuals with disabilities. The actual planning process will be overseen by an executive committee composed of non-Federal members. This committee will base much of its work on the deliberations of ad hoc subcommittees or panels. These panels will reflect the team structure of NIDRR. The membership of these panels will be representative of researchers, people with disabilities, providers, and administrators. The executive committee and panels have not been identified at this time because the contract for conducting the process has not yet been finalized. The long-range plan affords NIDRR the opportunity to work with people who have disabilities in developing a plan that identifies research areas that can be investigated. Additionally, this process will facilitate the development of products and produce knowledge which will, in turn, lead to the empowerment of people with disabilities.

A fourth purpose of the Project Directors' Meeting is to assist NIDRR in identifying topics that might be suitable for examination by NIDRR Consensus Panels. Individuals with disabilities, as well as those professionals serving them, need information on which to base decisions. Over the past ten to fifteen years, a considerable body of information has accumulated as a result of the NIDRR research program. The potential for fully utilizing the benefits of NIDRR research outcomes have been largely unrealized in the following areas: a) shaping the delivery of rehabilitative services, b) setting the standards for practice, and c) establishing expectations relative to the substance and quality of rehabilitative care received by persons with disabilities. The purpose of the Consensus Panels will be to communicate to rehabilitation practitioners and people with disabilities the consensus of opinion on important topics and issues within the disability and rehabilitation research community. Consensus statements or reports will be developed through careful studies of research, examination of expert opinion, and appraisal of input from individuals receiving these rehabilitative services. Three consensus panels are planned annually for the next three years. Initiation of the consensus panel process is an affirmation by NIDRR of the value of a) the work of its grantees, and b) the impact of the work of disability and rehabilitation researchers on the lives of people with disabilities.

Consensus statements are an important part of NIDRR's empowerment process. One of the primary requisites of empowerment is knowledge and the ability to make informed choices. The mission of NIDRR is to provide people with disabilities and their families the kinds of knowledge they need to become empowered and to increase the freedoms they

experience. Through published consensus statements which facilitate the acquisition of knowledge about standards of disability and rehabilitation care, individuals with disabilities can make more informed choices and become more active partners in their rehabilitative services program.

NIDRR GOALS

I would like to take this opportunity, since I have a somewhat captive audience, to share with you the goals I have established for NIDRR. The goals are as follows:

NIDRR Goal I: Increase the quality and quantity of input, advice, and consultation in the activities and planning of NIDRR from the following groups: people with disabilities, providers of rehabilitation and disability related services, rehabilitation and disability researchers, and developers of rehabilitation technology.

This meeting is an example of our intention to increase opportunities for input. Other examples in this endeavor include the public hearing that was recently held to assist in the development of priorities for Title II, Part C of the Technology-Related Assistance for Individuals with Disabilities Act of 1988 and the other public hearings that will be scheduled relative to the development of the long-range plan. A Dissemination Task Force has been appointed, and it met for the first time earlier this month. This task force will provide NIDRR with input regarding the dissemination of information to people with disabilities, providers of rehabilitation services, and researchers and engineers.

This is NIDRR's macro plan to increase input. But is it enough? The knowledge utilization research literature suggests that it is not. In order for people to effectively use the research findings, they must have adequate opportunity for discussion of issues affecting their lives. Various findings support the establishment of opportunities for the exchange of information throughout the research and dissemination process.

People with disabilities and their families should participate in designing and conducting disability and rehabilitation research. NIDRR intends to examine the way in which NIDRR-funded research is conducted. This examination will focus on exploring research models that involve both consumers and providers of rehabilitation services as active participants in the research process. Participatory research models:

1) emphasize researchers intensifying their contacts with the ultimate user or beneficiary of the research product;

2) focus on closing the gap between the researchers and the field -- both consumer and practitioner; and

3) offer ways for consumers and practitioners to participate in all phases of the research process from hypothesis development to dissemination of findings.

As disability and rehabilitation researchers, we must be sure that participatory research is made attractive. It should be because it is based on the rehabilitation service philosophy of the team approach. In the past, individuals with disabilities have regularly been included as a team member in rehabilitation treatment planning, therefore it is not such a large step to insure their participation in the disabilities and rehabilitation research process.

NIDRR Goal II: Increase the contributions which NIDRR makes to improvements in the quality of life and freedom experienced by people with disabilities.

This goal is the most elusive and yet the most important. It is the fundamental reason for NIDRR's existence and for the granting of its funds. How do we know if NIDRR is making these contributions? Both the Rehabilitation Research and Training Centers and the Rehabilitation Engineering Centers have assisted me in making some determinations in this important area. They have provided summaries of the ways their projects impact on the lives of persons with disabilities or those individuals who provide services to them. These statements have been most helpful since they provide a first step in this important assessment of the activities of NIDRR. The process of developing consensus statements will also assist in this area.

NIDRR Goal III: Improve the internal management of NIDRR, including the peer review process, monitoring of grantees, and the technical assistance skills of NIDRR staff through increased staff development.

All of your are, no doubt, aware of the increases activities NIDRR has undertaken to increase the monitoring of grants, cooperative agreements, and contracts. This activity has been very helpful to NIDRR management. I want to thank each of you for the fine spirit of cooperation demonstrated in the first three months of this process.

NIDRR staff development is an important team management goal. Each NIDRR staff member will have as part of the evaluation process and individualized development plan (IDP). The IDP will enable NIDRR staff to increase its technical skills and to be more aware of cutting issues in the field that they supervise.

Peer review is "the heart, apex, nadir, and trial of NIDRR." Effective October 1, 1990, there have been some significant changes in the peer review process at NIDRR. The first change was the creation of two rosters of peer reviewers at NIDRR. The first roster is the current list of names of peer reviewers. The second and new roster is a list of scientific reviewers. For every peer review panel, an additional person will be added to the standard number of reviewers per panel. This additional person will be an individual whose credentials place her or him on the science roster. Additionally, the number of applications a panel is asked to review on any one day will not exceed six for such competitions as Innovation Grants or Field-Initiated Research, and will be less for other competitions, such as Research and Training Centers and Research and Demonstration Projects. Each panel will receive one half day of training in the peer review panel meetings. After the completion of a competition and funding decisions have been made, a NIDRR in-house task force will review the comments of the peer review panelists for accuracy, completeness, and validity. In those cases where the peer review panelists did not meet the expected standards of performance for a peer reviewer, the panelist's name will be deleted from the peer review roster. This review process compliments the Department of Education regulatory policy requiring that one third of the peer reviewers be replaced annually with new reviewers, or at least with reviewers who have not been used in the past three years.

It is important that we examine the philosophical basis for the development of the Department of Education peer review policy.

> "A government's use of peer review presents a classic democratic conundrum, which is further complicated by the public value attached to freedom of expression in the American political system. Here, peer review processes must produce public decisions that are both well-informed and broadly participatory and that reconcile the protection of scientific and creative freedom of individual applicants with the necessity for governmental accountability to the general public. Recognition of the legitimate claims of both demands is a critical step toward managing this apparent paradox."
>
> "In a larger sense, controversies surrounding the public use of peer review processes cannot be resolved by single-minded appeals to either technical expert authority or to the power of political interests. Rather, any solution must be able to claim both expert and public legitimacy" (Wyszomirski, 1990).

The peer review process at NIDRR attempts to address both realms by the inclusion of people with disabilities and their family members on peer review panels. In many cases, these individuals are scientists who are well known and respected for their achievements in their disciplines.

NIDRR Goal IV: Increase the planning of NIDRR, especially as it relates to the five-year plan, the identification of priorities for research, training, dissemination, technological development, and the use of funds for all activities of NIDRR.

A lot has been said about planning of NIDRR, but I would like to add one or two additional comments. Planning is essential to progress in this field. You can expect more activities and requests for your involvement in the planning process.

NIDRR Goal V: Increase the dissemination and knowledge utilization activities of NIDRR.

The consensus panels and Dissemination Task Force are examples of this NIDRR activity. These kinds of activities will increase because they are essential for the empowerment of people with disabilities. The following quotation by James Madison very clearly demonstrates the importance of this goal:

> "A popular government without popular information, or the means of acquiring it, is but a prologue to a farce or a tragedy; or perhaps both. Knowledge will forever govern ignorance: And a people who mean to be their own governors must arm themselves with the power that knowledge gives."

To be repetitive, you and NIDRR are in the knowledge production business which is based on the principles of science. Good science is necessary if there is to be a product. I am emphasizing dissemination and knowledge utilization because they are essential to empowerment. True empowerment depends on knowledge. Knowledge production at the NIDRR depends on the scientific method with full participation of people with disabilities and providers of rehabilitation services. The ultimate recipients of the products you develop are people with disabilities.

Knowledge grants people with disabilities the ability to make informed choices and thus become empowered. Through the empowerment process, individuals with disabilities and their families will be able to hold both the providers of educational and rehabilitative services and NIDRR accountable for a disability and rehabilitation research program that benefits individuals with disabilities and their families.

Practitioners are an important part of the NIDRR dissemination market as well. User information statistics from National Rehabilitation Information Center (NARIC) indicate that about 40% of the users of NARIC data are practitioners. The results from NIDRR Vocational, Behavioral, and Social Sciences Team projects generate a body of knowledge to assist the

disability and rehabilitation professional in making rational decisions regarding treatment recommendations. Therefore it is important that research results not sit on shelves. Rather, they should be disseminated to practitioners so the latter can understand (1) the reason for the research, (2) the basic results of the research activity, (3) potential uses of the results in their service delivery environments, and (4) the steps necessary to acquire additional knowledge to help them in their daily practice of their professional skills (Modifications to Worksites and Educational Settings, Wichita State REC, 1990). Because dissemination activities are critical to the empowerment process, an examination of the weights and criteria vis a vis dissemination are under way at NIDRR.

NIDRR Goal IV: Enhance the research training program and other research activities of NIDRR with an emphasis on the inclusion of people with disabilities and members of underrepresented populations interested in physical medicine and rehabilitation and disabilities of low incidence.

I don't really want to comment on this goal today except to say that this is a system wide issue that I hope you will address to some extent in your deliberations.

NIDRR Goal VII: Assist the Assistant Secretary of OSERS in developing programs that help in fulfilling President Bush's and the Secretary of Education's National Education goals.

The undergirding principles for these goals are collaboration and team work. These goals cannot be achieved without team work and collaboration. The problems facing the disability and rehabilitation community are too great to be addressed by any single research institution, NIDRR alone, or by groups of people with disabilities. They require collaboration. I look forward to collaborating with you, and I hope you will join with NIDRR in working as a team to plan for the future. Our combined efforts will increase the pool of rehabilitation and disability researchers, and will meet the information and knowledge utilization needs of people with disabilities and their families, rehabilitation and disability related service providers, and disability and rehabilitation researchers. If we collaborate as a team, I believe that NIDRR can make significant strides in responding to the empowerment needs of people with disabilities.

William H. Graves, Ed.D.

References

1. Wichita State REC. (1990). Modifications to Worksites and Educational Settings.

2. Wyszomirski, M. J. (1990). The art and politics of peer review. The Grantsmanship Center Whole Nonprofit Catalog, Fall/Winter.

CHAPTER II

POPULATION DESCRIPTION

AND

CURRENT RESEARCH EFFORTS

DISABILITY POPULATIONS SERVED BY WORKSHOP PARTICIPANTS

The attendees at this NIDRR conference represented research studies relevant to a wide range of disability populations. The group reflected the needs of infants, children, youth, and adults with severe, multiple disabilities, late-onset hearing loss, mental retardation, long term mental illness, deafness, low vision and blindness, physical disabilities, strokes, chronic illness, and a host of other disabling conditions.

CURRENT RESEARCH FUNDED THROUGH THE NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

In the past ten years, NIDRR has enlarged its focus in four major areas of importance in the disability field: 1) Children; 2) Families; 3) Community Integration; and 4) Supported Employment.

In 1980, the then National Institute of Handicapped Research (NIHR) funded four early intervention Research and Demonstration projects that totaled approximately $520,000. In addition, there were two Research and Training Centers focusing on adults with mental retardation. These two centers were funded at approximately $600,000 per year. The work of the Centers was concerned primarily with developing prevocational skills and sheltered employment opportunities. There were also a few isolated Research and Demonstration projects pertaining to mental retardation. The Institute also was funding two Research and Training Centers which addressed the psychosocial rehabilitation needs of adults with long-term mental illness. These two Centers were jointly funded by NIHR and the National Institute of Mental Health (NIMH). NIHR's contribution to the Centers totaled approximately $750,000.

In 1990, NIDRR has a research program related to children, families, and community integration that is unique in the Federal government. This program consists of Research and Demonstration projects, Research and Training Centers, Field Initiated projects, and Innovative projects which center in the following areas:

1. Early intervention for infants and young children;

2. Psychosocial/developmental issues relevant to children and adolescents with disabilities and chronic illness;

3. Community integration of people with mental retardation and developmental disabilities;

4. Community integration of children and adults with emotional disabilities; and

5. Family support.

The activities focusing on children, community living, and families are authorized under the Rehabilitation Act of 1973, as amended.

The relevant projects are built on the premise that "rehabilitation" includes all the research, training, and service delivery activities that foster the independence, productivity, and social integration of children and adults with disabilities and provide for a range of community-based supports for the individual and her or his family.

Further, this research has been based on the philosophy that children and adults with disabilities are to be valued and respected for their abilities, individuality, and the positive contributions that each person makes to her/his family and community. Additionally, children and adults should have the right to live in their communities, in homes that are family-scale, with whatever supports are needed to maintain that person and the people that he/she calls, "family".

This particular research program crosses the life span and cuts across disabilities. NIDRR is the sole Federal agency that sponsors, within the same program area, research aimed at improving neonatal intensive nursery care for very sick infants while also funding a Research and Training Center for people with mental retardation who are aging. NIDRR is the only agency that addresses policy, intervention, and developmental research that will improve community services and practices affecting both children and adults with disabilities. NIDRR's research program for children, families, and community integration covers areas such as bronchopulmonary dysplasia in infants and young children, long-term mental illness in adults, mental retardation, traumatic brain injury, deafness and mental health problems, self-injurious behaviors, and cognitive coping styles in families.

The research that is sponsored by NIDRR in the area of children, families, and community integration has as its ultimate goal to develop strategies, models and materials that will support the child and/or adult with a disability. It is research that is <u>for and with people with disabilities and their families</u>. It is not research <u>on</u> people with disabilities. It is participatory research that respects people with disabilities and their families and does not intrude on their privacy and dignity. The research in this program area answers in the affirmative, "So what? Will this make a positive difference in the lives of people with disabilities?"

During the years while the research for children, families, and community integration was developing, another research thrust was equally pervasive. As the focus of the Office of Special Education and Rehabilitative Services increased on a new approach to work, Supported Employment, research on its efficacy and effect in relation to the needs, choices, and options of people with disabilities was carried out. With the assistance of NIDRR researchers, this concept has grown in seven years from "pie in the sky" to a positive, rewarding employment alternative that allows people with the most severe disabilities to participate in the competitive work force.

Interestingly, the Supported Employment concept of "job coaches" and "support" has led to other research where "living coaches" aid in the recovery and rehabilitation of people disabled by strokes. An emerging area of research, "supported living" and "supported housing," is gradually becoming part of this research focus. The concepts introduced have assisted researchers to develop programs wherein people with disabilities may have as much or as little support as needed and for varying amounts of time as they go about their lives in community settings.

The NIDRR Program Directory for Fiscal Year 1989 indicated that there were 110 projects monitored by Vocational, Behavioral, and Social Sciences staff. The focus of the research was infants, children, youth, and adults with disabilities and a commitment to enabling these persons to participate fully in community living, employment, and leisure activities. Broadly, the projects can be categorized as follows:

Community Integration	13
Supported Employment	11
Families	11
Infants, Children, and Youth	20
Vocational Rehabilitation	24
People with Sensory Disabilities	6
Rehabilitation Systems	2
Special Ethnic Populations	3
Dissemination	2
Small Business Innovation Research	13
Other	5

The NIDRR Program Directory for Fiscal Year 1989 reveals that the Vocational, Behavioral, and Social Sciences team of NIDRR monitored:

- 46% of the total NIDRR Research and Development projects;
- 50% of all the Rehabilitation Research and Training Centers;
- 49% of all the Innovation Grants;

- o 12% of the total Utilization grants;
- o 49% of all Field Initiated Research;
- o 3% of the Interagency Agreements;
- o 72% of the Small Business Innovation Research (SBIR) Phase I contracts;
- o 59% of the SBIR Phase II contracts; and
- o 10% of the other NIDRR contracts.

In total, $19,348,345 of the $64,710,465 NIDRR total funding for FY 1989 was spent in vocational, behavioral, and social sciences research. This is 30% of the total. In addition, $1,274,831 was contributed by other agencies. The most notable contributing agency was the National Institute of Mental Health which jointly funded four Research and Training Centers which were focused on mental health and one Field Initiated Research project on supported living.

Appendix A contains an overview of the types of NIDRR sponsored activities in the areas of vocational, behavioral, and social sciences research.

CHAPTER III

RECOMMENDATIONS FOR FUTURE RESEARCH

AND

RECOMMENDATIONS FOR RESEARCH CONSENSUS CONFERENCES

RECOMMENDATIONS FOR FUTURE RESEARCH AND RECOMMENDATIONS FOR RESEARCH CONSENSUS CONFERENCES

During the conference, six groups met to discuss present research and to make recommendations for further research efforts. Group efforts were organized as follows: Group I, Families; Group II, Behavioral/Educational Concerns; Group III, Community Living I; Group IV, Community Living II; Group V, Vocational Rehabilitation; and Group VI, Supported Employment and Traumatic Brain Injury.

Analysis of the group reports revealed that there were ten central research and training area themes:

- Outcome Research;
- Intervention Research;
- Research for New and Underserved Populations;
- Systems Change Research;
- Research on Self-Determination and Consumer Participation;
- Policy Research;
- Attitudinal Research;
- Research to Improve Training;
- Multicultural Research and Training; and
- Technology Transfer.

There were also recommendations for Consensus conferences.

There was general agreement among the groups on several research content areas. First and foremost, flip chart notes and notes from participant/recorders indicate that researchers agree that research under the Rehabilitation Act needs to encompass more than just vocational outcomes. As Dr. Graves pointed out in his summary, responding to the need for rehabilitation research is like using a road map; there are many different routes that will end in the same destination. Such diverse routes include the following:

Full Participation by Persons with Disabilities

- There is a need for persons with disabilities to fully participate in school, work, residential living, and play in the community.

- Studies should be conducted which focus on housing needs, social integration activities, and redirecting challenging behaviors.

Infants and Children with Disabilities

- Research that focuses on infants and children with disabilities and their families may, in the long run, prove the most productive in preparing citizens with disabilities to assume their full roles in the community.

Longitudinal Research

- There is a need for longitudinal research. While it is recognized that longitudinal studies are being conducted by many Rehabilitation Research and Training Centers, even these efforts are limited to five years at a time because of Departmental requirements. The need was apparent for research that follows people with disabilities over the life span.

Qualitative and Quantitative Research

- There is a need for both rigorous quantitative and qualitative research designs. Quantitative research is required to fulfill the research design requirement of some areas of study. At the same time, researchers who study social processes and interactions that lead to integration and policy changes rely on qualitative designs. A large number of NIDRR projects implement both methodologies. The attendees felt that NIDRR reviewers should be sensitive to the need for rigorous quantitative and qualitative research designs.

Multicultural, Diverse, and Low Incidence Populations

- Evident in the group discussion was the need for research in multicultural area, which includes groups from low-incidence, ethnic minorities, Native American and Hawaiian American tribes and families, and other culturally-defined people such as the deaf community. It was observed in almost every working session that rehabilitation services often must be realigned in order to meet the needs of members of other cultures who have disabilities.

- It is interesting to note that the issue of the stigma attached to disabilities is still predominant in the minds of researchers. This issue was one of the first tackled by researchers and service providers when the era of rehabilitation began. It is obvious, however, that the disability field still needs to concentrate energies on heightening the public's awareness of the capabilities and strengths that children and adults with disabilities have.

Policy and Systems Change Research

- There is a strong, continuing need for policy and systems change research. It is recognized, for example, that funding mechanisms often dictate the services received by people with disabilities. They, in fact, usually determine how long and to what degree services are provided. The researchers felt that there should be continuing focus on research that may lead to policy and regulatory systemic changes with regard to funding and service provision.

For example; Group I had in-depth discussions focused on the need for outcome-oriented research, in particular, how research would: 1) benefit the person with the disability; 2) benefit the family member; and 3) benefit society in general. The members of the group also spent considerable time discussing the need for building research, training, and service delivery systems within a "family-centered" approach. This approach is founded on the philosophy that families are the center of service systems, and therefore services should revolve around the family, supporting the child or adult with the disability as well as her/his family unit. This is a concept that has been emerging in the delivery of medical services to chronically ill children and it is catching on in other types of disability programs. Group I urged NIDRR to sponsor research that would validate the model across the lifespan.

This group also discussed the need to expand and modernize the definition of "family" since there are so many non-traditional configurations in today's society. Time was spent discussing research that would address the unique needs of single parents, substance-abusing parents, and different ethnic, cultural, and racial groups. Although Group I devoted much of its attention to families of infants, children, and youth, there was also discussion of families with adult members with disabilities. While the rehabilitation emphasis has often been on the individual with a disability, it is recognized that this person is usually part of a family system. Research questions involved how to ensure that the family is an integral part of the rehabilitation plan for each person with a disability. Other family-centered discussions focused on parents with disabilities and the needs which they may have to assist with child-rearing. This research topic is very broad in that the type of disability directs the needs of individual parents, e.g., parents with physical or sensory disabilities may need assistance in the form of technology or personal

aides whereas parents who are mentally retarded may need on-going support in decision making and child rearing practice.

In each of the groups, there was also discussion about participatory research and ways in which people with disabilities can participate in conceptualizing, designing, implementing, and evaluating research which involves them. Discussion also centered on the dissemination of research findings with several groups pointing out the importance of moving the information as quickly as possible to individuals with disabilities, families, service providers, and Federal, state, and local planners.

Outlined below are synopses of the recommendations for research and for consensus conferences by each group:

RECOMMENDATIONS BY GROUP I: FAMILIES

Outcome Research Recommendations

- Investigate cultural definitions of health, illness, and disability as these variables relate to the outcomes of families with special needs.
- Identify variables or factors contributing to the success and well-being of families with special needs.
- Develop measures of positive family functioning.
- Conduct longitudinal studies of high-risk pre-term infants through school age, across disabilities.
- Investigate the ways in which families identify their strengths, resources, and needs compared to how professionals identify them in the same families.
- Study the role family perspectives and values play in supported employment and supported living.

Intervention Research Recommendations

- Investigate the etiology and prevention of challenging behaviors in children.
- Study the roles that settings and events play in the development of challenging behaviors, including assessments and program options.
- Conduct longitudinal lifespan research across disabilities to better understand family functioning.
- Conduct longitudinal studies of high-risk, pre-term infants through school age across disabilities and etiology.
- Investigate the ways in which families identify their strengths, resources, and needs compared to how professionals identify them in the same families.
- Identify the most effective and socially validated support strategies that enable children and adults with challenging behaviors to be fully included in their families and communities.
- Study, develop, and evaluate strategies for supporting parents who are mentally retarded.

- Investigate the effectiveness of in-home interventions in the families of children with serious emotional disorders.

- Investigate the hierarchies and sequences of cognitive coping strategies in families with special needs.

Research Recommendations Involving New and Underserved Populations

- Identify factors contributing to child maltreatment across cultures and develop culturally appropriate interventions.

- Identify and evaluate strategies for effectively supporting single parents whose children have special needs.

- Identify and evaluate strategies for effectively supporting families where one or more members is a substance abuser and whose children have special needs.

Systems Change Research Recommendations

- Conduct studies of permanency planning legislation across disabilities for children with special needs.

- Identify effective components of family centered service delivery systems across the life span.

- Conduct longitudinal studies of high-risk, pre-term infants from newborn to school age of various etiologies.

Research Recommendation on Self-Determination and Consumer Participation

- Identify and evaluate strategies and models for teaching children with special needs self-management skills.

Policy Research Recommendations

- Investigate and evaluate various respite care programs and models on a state-by-state basis, with particular attention to legislatively mandated programs.

- Investigate the role of poverty on disabling conditions, particularly among different ethnic and cultural groups.

- Identify the characteristics of an effective family support program.

- Identify the enabling and disabling regulations and legislation that impact on family centered care.

- Conduct state-by-state analyses of laws, policies, administrative procedures, and practices that result in families relinquishing custody of children and youth with emotional disorders and medical conditions in order to receive necessary services; develop strategies for overcoming the barriers to in-home care.

- Document cost and beneficial outcomes of family support programs on a state-by-state basis.

Attitudinal Research Recommendation

- Study professionals' beliefs about families' cognitive coping efforts and their relationship to the quality of parent-professional relationships.

Research Recommendations on Improving Training

- Develop, evaluate, and disseminate training strategies based on family-centered care models.

- Identify and evaluate strategies that will enable professionals to convey to families state-of-the-art information about the positive, long-term outcomes possible for babies with severe disabilities, using language that is useful and helpful to families.

Multicultural Research and Training Recommendation

- Identify cultural definitions of ability and disability and their impact on child development.

Technology Transfer Recommendation

- Develop and implement strategies for disseminating jargon-free research findings to families, community-based service providers and practitioners.

Consensus Conference Recommendations

- What elements comprise the family-centered approach? How can this approach be provided across the life span?

RECOMMENDATIONS BY GROUP II: BEHAVIORAL/EDUCATIONAL

Outcome Research Recommendations

- Sponsor longitudinal research in order to document the outcomes of various interventions for people with disabilities.

Intervention Research Recommendations

- Study and evaluate positive approaches to managing challenging behaviors.
- Sponsor longitudinal research on interventions that increase the capabilities of children and adults with disabilities to participate fully in school and community life.

Systems Change Research Recommendation

- Develop methods for improving access to community-based, affordable, and accessible mental health services for children and adults.

Multicultural Research and Training Recommendation

- Develop and evaluate strategies to improve the recruitment and training of personnel within a multicultural perspective.

Consensus Conference Recommendations

- What methodological designs are most appropriate for different types of settings and populations?
- What are the most effective strategies and benefits for cross-site collaboration in research?
- What are the innovative alternative options that go beyond Supported Employment to assist people with disabilities to participate fully in the competitive work environment?
- What are the best early intervention strategies for children at risk for disability and their families?
- What research policies promote maximum impact on long-term, programmatic research, research funding, collaborative research, joint funding of priorities, cultural and minority issues, increased training of researchers, establishing methodologic standards for evaluating outcome research, and provision of opportunities for NIDRR grantees to share research findings and challenges?

RECOMMENDATIONS BY GROUP III: COMMUNITY LIVING I

Outcome Research Recommendations

- Conduct longitudinal life span studies that address the outcomes of various interventions in the lives of people with disabilities.

- Develop and evaluate assessments and strategies that are consistent with community presence and participation in order to measure the degree of community participation by people with disabilities.

Intervention Research Recommendations

- Develop and evaluate positive approaches to management challenging behaviors in natural community settings.

- Identify strategies which enable adults with disabilities to become effective mentors for families with young children with disabilities.

Research Recommendation Involving New and Underserved Populations

- Study the impact that culture, geographic location, and group mores have on the definition and implementation of community integration strategies within minority ethnic groups.

Systems Change Research Recommendations

- Investigate the way in which service providers and agencies define "disabled" and how services are then provided.

- Investigate state policies and laws across disability groups with regard to funding mechanisms for providing community-based services.

Research Recommendation on Self-Determination and Consumer Participation

- Develop and evaluate methods to enhance empowerment and self-determination for people with disabilities emphasizing access, consumer management, ownership and coordination of future planning, day-to-day activities, work, residential options, etc.

Attitudinal Research Recommendations

- Develop strategies for effectively reducing the negative perceptions (and stigma) of people with disabilities by the general public.

Research Recommendation on Improving Training

- Develop strategies that will improve recruiting, training, and retention of competent personnel who work in community-based programs for people with disabilities.

Multicultural Research and Training Recommendation

- Develop strategies for improving the training of professionals and service providers so that they are culturally sensitive and aware of the population with which they are working, including sensitivity to cultural differences and disability differences.

Technology Transfer Recommendation

- Develop strategies that will ensure the successful transfer of assistive technology devices from the laboratory to the consumer, including mechanisms for working with varying socioeconomic and cultural groups.

Consensus Conference Recommendations

- What are effective strategies to ensure that consumers and their families are involved in the conceptualization, design, implementation, and evaluation of research?

- What are appropriate methodologies to study the interaction of people within specific environments (e.g., people with deafness within the deaf culture and in other settings; or people with physical disabilities in remote, rural settings and in cities).

RECOMMENDATIONS BY GROUP IV: COMMUNITY LIVING II

Outcome Research Recommendations

- Investigate the nature and processes of adjusting to disability and various coping mechanisms used by persons with disabilities.
- Conduct comparative studies of models, strategies, interventions used in the rehabilitation process.
- Investigate satisfaction outcomes as determined by the participation of people with disabilities in their communities using the perspectives of consumers, families, and members of informal support networks.

Intervention Research Recommendations

- Identify, study, and evaluate interventions that enhance the economic development capabilities of people with disabilities.
- Develop and evaluate strategies for successful social integration, relationship-building, and networking by people with disabilities.
- Identify the factors that lead to successful supported living and supported housing options for people with disabilities.
- Identify strategies that will support people with disabilities who are parents.
- Conduct research that studies family issues such as transitions, social support systems, coping skills, and strategies over the life span.

Research Recommendations on Self-Determination and Consumer Participation

- Develop strategies that will enable consumers to express choices and preferences regarding employment options.
- Identify the characteristics of exemplary consumer driven service delivery systems and best practices used in creating them.

Policy Research Recommendations

- Investigate the incentives and disincentives to inter-system collaboration that will result in improved community based services.

- Identify state laws, policies, administrative procedures, and practices that are facilitative of or barriers to the provision of rehabilitation services.

Attitudinal Research Recommendation

- Identify methods and models for effectively reducing social stigma across ethnic and cultural groups and disability populations.

Research Recommendation on Improving Training

- Develop strategies and models for recruiting, training, and retention of competent staff who are aware of cultural diversity among people with disabilities.

Technology Transfer Recommendation

- Develop and implement methods for rapidly disseminating and utilizing research findings.

Consensus Conference Recommendations

- What are the appropriate methodologies and instruments to use when studying community living?

- What are the emerging effective roles of consumers as colleagues in research, training, and service delivery?

- What are exemplary approaches for disseminating research findings and implications? What strategies reflect cultural relevance and the relevance of research to culturally diverse populations?

RECOMMENDATIONS BY GROUP V: VOCATIONAL REHABILITATION

Outcome Research Recommendation

- Investigate the way in which employment decisions regarding a person with a disability affect his/her family and the work and home base roles of others in the family.

Intervention Research Recommendations

- Investigate how safety and health conditions at the workplace contribute to the prevention of disability, employment, and the return-to-work opportunities.

- Study how workplace mechanisms such as medical departments, recruitment procedures, and collective bargaining contracts, promote or prevent employment, return to work, retention and career advancement for persons with disabilities.

Research Recommendation Involving New and Underserved Populations

- Conduct research to determine the most effective way to utilize existing personnel to work with new populations such as persons who are HIV positive, people with traumatic brain injury, etc.

Systems Change Research Recommendation

- Document the relationship between employment and qualifying for eligibility for publicly funded support such as benefit payments, health care, counseling, and other services.

Research Recommendations on Self-Determination and Consumer Participation

- Identify, study, and evaluate ways in which people with disabilities can access information systems in order to make informed career choices.

Policy Research Recommendations

- Identify exemplary models of alternative processes used in the transition of students from school to work or from sheltered employment to competitive or supported employment.

- Identify the impact of case management, interagency coordination, long-term tracking, utilization of home and vocational supports, and program evaluation on benefits and outcomes to the individual.

Research Recommendations on Improving Training

- Identify, evaluate, and disseminate information about optimal preservice, in-service, and continuing education curricula for rehabilitation counselors.

- Develop methods for effectively utilizing existing rehabilitation personnel to fill existing vacancies and to meet emerging requirements of serving new populations.

Technology Transfer Recommendations

- Develop strategies for rehabilitation counselors which utilize the application of technology in a) the planning and decision making process, and b) assessment skills and other relevant areas.

- Document the manner in which information from vocational assessments, planning, and placements is utilized to optimize successful vocational placements.

RECOMMENDATIONS BY GROUP VI: SUPPORTED EMPLOYMENT AND TRAUMATIC BRAIN INJURY

Outcome Research Recommendations

- Identify the rehabilitation service components in supported employment models that are most facilitative of positive employment outcomes.
- Conduct consumer and cost benefit studies relevant to various supported employment models.
- Identify the variables that lead to successful client outcomes.
- Identify the variables that lead to effective job coaching performances as measured by client outcomes.
- Document the variables that lead to long-term patterns of social interactions between employees with disabilities and employees without disabilities.

Intervention Research Recommendations

- Study the efficacy of natural supports vs. traditional supported employment methods relative to placement, outcome, retention, and cost benefits.
- Identify the optimal role of family, consumer, business, community, and rehabilitation staff in a state-of-the-art supported employment program.
- Develop and evaluate innovative approaches to and models of supported employment.
- Develop case difficulty/disability severity variables across disability groups in order to compare outcomes, retention, and cost benefit data.

Research Recommendations Involving New and Underserved Populations

- Evaluate supported employment models designed to serve new and underserved populations such as people with traumatic brain injury or people who are HIV positive.

Systems Change Research Recommendations

- Investigate the ways in which flexibility in funding affects supported employment service delivery models.

- Develop and evaluate strategies for long-term funding of supported employment options.

Research Recommendations on Self-determination and Consumer Participation

- Develop and evaluate strategies for consumer involvement in supported employment.
- Identify and evaluate models that enable consumers to have options and express their choices and preferences.
- Investigate the perceptions of supported employees toward their co-workers without disabilities.

Policy Research Recommendations

- Develop methods for examining retention rates in supported employment.
- Analyze state laws, policies, and practices that determine eligibility for and access to supported employment programs.
- Identify, study, and disseminate variations in individual employment supports for people with disabilities; this would include the development of individual supports in rural, small town, and urban areas.
- Investigate the role of volunteerism in supported employment service delivery.

Attitudinal Research Recommendation

- Investigate the perceptions of employees without disabilities of a) supported employment, and b) employees with disabilities.

Technology Transfer Recommendation

- Develop strategies to ensure immediate, widespread dissemination of research findings to consumers and service providers.

Consensus Conference Recommendation

- How can research assist in developing supports and services to facilitate full participation in supported employment by people with disabilities?

CHAPTER IV

REFLECTIONS ON CONFERENCE RECOMMENDATIONS

BY

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U.S. Department of Education

REFLECTIONS ON CONFERENCE RECOMMENDATIONS

I would like to share some observations that I made while I have listened to and participated in your discussions. My first general observation is that the pursuit of state-of-the-art knowledge in rehabilitation research can be compared to using a large road-map. As time passes, more and more routes make it possible to achieve the ultimate goal of independence, self-determination, and productivity for all citizens with disabilities.

In some sense, I have the feeling of driving down the Parkway and trying to fold the road map back into its neat little package, and I know darn well that I will have an accident if I try to get it back into that neat little package. Another thing about road maps is that they give you a lot of ways to get to the same place. I think that what has been apparent in the discussions that I have heard here is the diversity of research approaches that supports the concept of what a road map is about. That is also what NIDRR's Long-Range Plan will be. It will be a map with many routes that will lead NIDRR and rehabilitation research to programs that support, empower, and enhance freedom, productivity, and self-determination for all people with disabilities. I heard most of you at this conference agree with and support that notion, and I thank you for that.

Somebody asked me what this research plan is going to contain. We are going to state the rationale for having disability and rehabilitation research. I think that you stepped around this issue in your discussions, but we have to address it in our Long-Range Plan. We are going to answer the questions, "Why do we need this special brand of research?" and " How is it different from other kinds of social, medical, and vocational research that is conducted in our country?" As I have listened and participated, I think that all of you have given us some suggestions and ways we need to address these two central and important questions.

The other issues that I have heard include a great deal of concern about new paradigms of research and methodology and how we conduct research to address new issues that are emerging. What you are telling me is that the ways we have done things in the past have not always been successful. We may have made the error of asking the wrong question or maybe asking it in the wrong way. We are going to address that issue in the Long-Range Plan, and I appreciate your honesty.

The other thing I heard a great deal about was the issue of outcome research, particularly outcome research across the lifespan. These are the kinds of questions that we at NIDRR are interested in, and they are ones that will need to be addressed in terms of our Long-Range Plan.

I was impressed that you emphasized the fact that disability and rehabilitation research needs to span the community, bringing in people from other areas in order that we might have better vision and better understanding of the contributions of other fields to our work. I think this is good: It's good for us, and it's good for people with disabilities. It will be considered in developing the Long-Range Plan.

I would like to give you some brief information on the Regional hearings that NIDRR will conduct as part of the planning process. There will be six hearings, but, due to Federal contracting rules, I cannot, at this time, tell you where the sites will be. I can tell you, however, that there will be hearings in the Southwest, Midwest, Northwest, Southeast, and New England regions. Washington, D.C. will serve as the Mid-Atlantic site. The exact locations will be announced in the Federal Register. We are sending out 1,000 letters inviting people to participate in the Long-Range planning process. We have to have widespread participation. I am asking each of you, when you return home, to share this information with your community organizations, people with disabilities, service providers, family groups, and other interested people. Urge them to attend the regional hearing in your area. If they cannot attend, encourage them to send NIDRR their written comments. We need their input.

The NIDRR Long-Range Plan will not be one person's plan. It is a product that will be developed by people with disabilities, researchers, families, service providers, and concerned citizens.

William H. Graves, Ed.D.

APPENDIX A

GROUP SUMMARIES

FIGURE 1
Project Summary

Adult–Focused Research		Child–Focused Research		Social Skills and Network Building		Family Focused Issues		Policy Focused Issues	
1– Assessment of individual functioning, care providers, and environment	D. Goebert, Univ. of Hawaii	2- Rehabilitation and developmental care of U.L.B.W. newborn	H. Als, Boston Children's Hospital	3- Community partners	D. Bateman, J. Williams, Univ. of Kansas	3- Family friendly: IFSP Methods	J.A. Summers, Univ. of Kansas	3- A survey of state legislation for family support programs	H.R. Turnbull, Univ. of Kansas
6- Individuals disabled by ocean related injuries	D. Goebert, Univ. of Hawaii	1- Assessment and treatment of abuse in handicapped children	R. Ammerman, Univ. of Pittsburgh	7– Social competency assessment	S. McConnell, Univ. of Minnesota	3- Family enhancement project	J. Sheldon, Univ. of Kansas	4- Development of respite care materials for families with children who have disabilities	M.L. Licwinko, CSR Inc.
6- Disability among elderly people in Hawaii	J. Varney, Univ. of Hawaii	5- Intervention strategies for managing severe excessive behavior	Univ. of Oregon, et al.	7- Promotion of self-care in children with chronic illness	R. Blum, Univ. of Minnesota	3- Research on teaching cognitive coping skills to families	S. Behr, Univ. of Kansas	6- Cross-cultural studies of persons with long-term disabilities	J. Varney, Univ. of Hawaii
6- Exercise and recreation as rehabilitation strategies	J. Varney, Univ. of Hawaii	5- Outcome measures to evaluate behavioral interventions	Univ. of Oregon, et al.	7– Social networks for children with disabilities	B. Abery, Univ. of Minnesota	3- Parent-to-Parent National Survey	B. Santelli, Univ. of Kansas	6- Pacific island culture and disability	D. Anderson, Univ. of Hawaii
6- Back injury study	J. Wang, Univ. of Hawaii	5- Functional analysis	Univ. of Oregon, et al.			3- Reasonable efforts in permanency planning	C. Petr, Univ. of Kansas	6- Pacific island rehabilitation service delivery	M. Fitzgerald, Univ. of Hawaii
		5- Generalization of intervention gains	Univ. of Oregon, et al.			3- Family support program evaluation	H.R. Turnbull, Univ. of Kansas	6- Off. Islands medical referral system	H. Yeu, Univ. of Hawaii
		5- Technology utilization	Univ. of Oregon, et al.			7- Family reorganization	J. Patterson, Univ. of Minnesota	6- Assistive technology for Micronesia	M. Fitzgerald, Univ. of Hawaii

GROUP I: FAMILIES - OVERALL GROUP SUMMARY
FIGURE I (cont'd.)

Adult-Focused Research		Child-Focused Research		Social Skills and Network Building		Family Focused Issues		Policy Focused Issues	
		7- A longitudinal study of children with chronic illness and disability	R. Blum, J. Patterson, Univ. of Minnesota			7- Families caring for children who are medically fragile at home	B. Leonard, Univ. of Minnesota	6- Survey of health care utilization and out-of-pocket expenses	P. Newacheck, UCSF, P. McManus, Washington, D.C.
		7- A longitudinal study of children who are medically fragile	B. Leonard, Univ. of Minnesota			7- Family definitions of health and disability: Ethnocultural variation	J. Patterson, Univ. of Minnesota	7- A survey of children in alternative care settings	P. West, Univ. of Washington
		7- Siblings of children with disabilities	B. Leonard, Univ. of Minnesota			7- Assessment of family-community fit	J. Patterson, Univ. of Minnesota	7- Analysis of state policies which impact on children and youth with disabilities	A. English, National Youth Law Center
						7- Needs of families of color who have children with disabilities	B. Price, PACER	7- Costs and outcomes for chronically ill children: A policy analysis	P. McManus, Washington, D.C. P. Newacheck, UCSF
						7- Self-advocacy skills for adolescents with disabilities	A. Halper, Univ. of Minnesota	7- Barriers to appropriate services: A legal framework for financing	A. English, National Youth Law Center

CODE OF PROJECTS AND RTC's

1. University of Pittsburgh, Western Pennsylvania School for the Blind, Pittsburgh, Pennsylvania
2. Children's Hospital, Boston, Massachusetts
3. The Beach Center, Lawrence, Kansas
4. CSR, Inc., Washington, DC
5. RTC on Community-Referenced Technologies for Non-Aversive Behavior Management, University of Oregon, Eugene, Oregon
6. Pacific Basin RTC, University of Hawaii, Honolulu, Hawaii
7. Center for Children with Illness and Disability, University of Minnesota, Minneapolis, Minnesota.

GROUP II: BEHAVIORAL/EDUCATIONAL CONCERNS OVERALL GROUP SUMMARY

Wide-ranging issues are being addressed in the research represented by this group. Throughout, there is a clear emphasis on topics of relevance to successful community integration. The projects focus on disabilities in early childhood, in school-aged populations, and in adulthood. Although there is some overlap of both populations and research questions, the abbreviated review presented below is organized according to the primary point in the lifespan of participants.

EARLY CHILDHOOD

Kamehameha Schools, Center for Development in Early Education, Honolulu, HI

> The Native Hawaiian Hearing Project is testing a hypothesis that demonstrable improvement in the language competence of children can be achieved by the introduction of a communication program into preschool classrooms of 120 children, and 100 children are being monitored as a comparison group.

University of California, Department of Psychology, Los Angeles, CA

> An early intervention project, with extensive controls, is systematically replicating earlier findings of major improvements by young children with autism; in the current project, the benefits of an intensive community-based early intervention program are being studied in young children with mild to moderate retardation. An intensively treated (30 hours or more of 1:1 per week for 2 or more years) group of 20 children, in areas of intellectual, educational, and social skills.

University of Massachusetts/Amherst, Department of Psychology, Amherst, MA

> The definition, assessment, and treatment of social behavior in young children with autism is being studied in an integrated preschool. Descriptive research is focused on ongoing probabilities of naturally-occurring social behaviors. An interdisciplinary team is providing divergent input on key differences in social behavior of children with autism and typical children. Interventions are aimed at promoting generalized gains in core autism deficits.

SCHOOL-AGED CHILDREN AND YOUTH

University of South Florida - Florida Mental Health Institute, Tampa, FL

The Research and Training Center for Children's Mental Health is conducting a series of studies of children and adolescents with serious emotional problems, including:

- a large-scale (N=812) observational study of the characteristics, functional levels, receipt of services, and outcomes for youngsters (ages 8 to 18) from six states;
- a two-year longitudinal analysis of the efficacy of six community-based treatment programs that have been identified as exemplary alternatives to traditional residential treatment settings;
- an assessment of the relationship between functional competencies and key outcomes;
- a study of the factors associated with successful transitions from school to work, and from family or institutional living to independent living;
- development of a methodology for state-level decision makers to estimate the level of need for components in a comprehensive system of care;
- a study of financing options and fiscal incentives and disincentives to community and home-based treatment;
- identification of model programs and exemplary practices to assist youth in transitions from school to work and independent living.

University of Kansas, Institute for Research in Learning, Lawrence, KS

A project is underway to develop and validate a set of three teaching routines that secondary mainstream teachers can use to enhance the performance of students with learning disabilities in their classes. Teaching routines are aimed at facilitating student memory, enhancing understanding of relationships, and on building a knowledge base that improves acquisition.

St. Luke's/Roosevelt Hospital Center, Developmental Disabilities Center, New York, NY

The relationship between cognitive abilities and communication behaviors is being studied in 140 children (ages 3-15) with multiple disabilities, including mental retardation. Assessment protocols and intervention software is also in development.

University of Vermont, Department of Psychiatry, Burlington, VT

A comparison of the competencies and behavioral and emotional problems of 6-16 year old children designated as Seriously Emotionally Disturbed or Learning Disabled is being secured from a database using the Child Behavior Checklist and the Teacher's Report Form, in conjunction with history information. The validity of a standardized clinical interview for discriminating children with Severe Emotional Disturbance from children with Learning Disabilities is being tested with 72 children (ages 6-11 years) from each group, along with 72 normal children.

ADULTHOOD

Howard University Research and Training Center for Access to Rehabilitation and Economic Opportunity, Washington, DC

The Howard University Research and Training Center for Access to Rehabilitation and Economic Opportunity is conducting large-scale research on the compounding effects of minority group status, economic hardship, and disability, including:

- a study of the prevalence, incidence, and impact of disability and other related demographic variables among ethnic minorities;
- a study of attitudinal factors which are related to the under-utilization of rehabilitation facilities and services among ethnic minorities;
- an examination of factors which facilitate and increase employment success among minority persons with disabilities, and development of a resource file to facilitate utilization of mentors, contacts, and networks;
- an assessment of the prevalence of depression and suicidal ideation in disadvantage adolescents, and an analysis of related factors;

- an examination of variables which influence and reduce substance abuse, and identification of approaches useful with disabled non-white persons;

- a study of demographic and social support factors that affect the coping of minority parents of children with disabilities;

- a study of variables related to positive employment outcomes among ethnic minority populations, to develop a predictive model.

Virginia Commonwealth University, Richmond, VA

Highly successful adults with learning disabilities have been compared with moderately successful adults with learning disabilities, to discover key themes differentiating those with vocational success.

GROUP III: COMMUNITY LIVING - OVERALL GROUP SUMMARY

FIGURE II

AGENCY	PRINCIPAL INVESTIGATOR(S)	TITLE OR RESEARCH OR TRAINING PROJECT	SUMMARY/FOCUS
American Foundation for the Blind	Laura Cummings, M.A. Corinne Kirchner, Ph.D.	Blindness/Low Vision Needs Assessment and Rehabilitation Materials Development on the Hopi Reservation	Conduct a needs assessment of blind/visually impaired Native American Hopi Indians through observations and interviews. Produce audiotapes in the Hopi language describing how to complete daily tasks with little or no vision. Prepare a report on the methodology of conducting culturally appropriate projects and disseminate this information through journal articles and presentations.
Oval Window Audio	Norman Lederman, M. S.	Development of an Improved Assisted Listening System for Persons with Hearing Impairments	Design, develop, field test, and commercialize a new assisted listening system product named "3-D". This patented induction loop significantly eliminates background noise by transmitting the desired sound directly to the person using a hearing aid. Users can receive the signal without suing special receivers.
San Jose University S.E.E. Center for the Advancement of Deaf Children	Gerilee Gustasson, Ph.D.	Sign Skills Evaluation	Evaluation panels explore validity/reliability of previously developed (1986-87) expressive sign skills evaluation for teachers and educational interpreters.
Syracuse University Research and Training Center on Community Integration for People with Developmental Disabilities	Steven J. Taylor, Ph.D.	RTC on Community Integration for People with Developmental Disabilities	Research activities include state deinstitutionalization practices, funding coordination, agency practices, and strategies to integrate people in the community, recruitment, training, and retention of program staff, natural environments, integration in generic social service programs, and establishment of database on community integration. Training focuses on graduate and leadership training, development, and national dissemination of materials (i.e., books, monographs, reports, articles, guides) to policymakers, professionals, service providers, parents, and people with disabilities.
University of Arizona/Tucson Native American Research and Training Center (NARTC)	James Organist, Ph.D. Inez Tucker, Ed.D.	Culturally Sensitive Assessment Model	Development of culturally sensitive vocational assessment battery for American Indians. Review of literature; survey of current assessment practices; development and field testing of model; evaluation of analysis of model; dissemination of model.
University of Arizona/Tucson NARTC	Carol Locust, Ph.D.	Rehabilitation Workshops	Define the rehabilitation training needs of American Indians with disabilities, and design a series of workshops to address these needs. Products from workshops will be disseminated in the form of training materials, manuals, articles, etc.
University of Arizona/Tucson NARTC	Paul Skinner, Ph.D. Carol Locust, Ph.D.	Attitudinal Barriers to Service Delivery	Develop methods to determine and resolve attitudinal barriers in vocational rehabilitation service delivery to Native Americans. Determine the nature and significance of these barriers from psycho-socio-cultural perspectives of both Native American and mainstream cultures. Attitudinal barriers will be defined in a cognitive causal model and strategies developed and implemented to resolve them.

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GROUP III: COMMUNITY LIVING - OVERALL GROUP SUMMARY

FIGURE II (Cont'd)

AGENCY	PRINCIPAL INVESTIGATOR (S)	TITLE OR RESEARCH OR TRAINING PROJECT	SUMMARY/FOCUS
University of Arizona/Tucson NARTC	J. R. Joe, Ph.D. D. L. Miller, D.S.W.	Sociocultural Views of Work, Risk, Occupations, Disability, and Rehabilitation.	Comparison study of sociocultural views of risk, work, disability, and rehabilitation of American Indian workers and the views of their Indian and non-Indian vocational rehabilitation counselors. Study examines how cultural and social factors impact the use of vocational services. Research includes employment histories, prevalence of work-based disabilities, and workers' knowledge and use of vocational rehabilitation services.
University of Minnesota Research and Training Center on Community Living	Robert N. Bruininks, Ph.D.	RTC on Community Living: General Overview.	Research activities focus on housing options, new options for programs and services, strategies for families and service providers to use in improving social integration. Training activities focus on inservices for professionals and paraprofessionals, development of materials, technical assistance to staff, preservice training, preparation and dissemination of documents (i.e., technical reports, books, articles, and practical guides). The Center has developed a computerized integrative data base library.
University of Minnesota Research and Training Center on Community Living	Mary F. Hayden, Ph.D. Charlie Lakin, Ph.D.	Minnesota Longitudinal Study.	To summarize the state of current knowledge, key questions related to deinstitutionalization, and issues in increasing and improving community living opportunities and the implementation of community placement and support of persons with mental retardation and related disabilities.
University of Minnesota Research and Training Center on Community Living	Robert Bruininks, Ph.D. David Johnson, Ph.D. Martha Thurlow, M.A. Brian Abery, Ph.D.	Enhancing the Social Networks of Persons with Mental Retardation.	To study and promote, where appropriate, the formal and informal interpersonal and social networks of adults with mental retardation.
University of Minnesota Research and Training Center on Community Living	Joe Reichle, Ph.D.	Communication Disorders.	Several studies concerned with: a) review of the literature on communication alternatives to excessive behaviors, b) the development of functional response classes within communicative intents, c) a description of the differential use of rejecting utterances as a function of the learner's prior history with the item, d) the determination of the relationship between excessive behavior and the generalized use of socially acceptable behavior, e) the establishment of the conditional use of existing communicative behavior, f) the examination of the variables influencing the establishment of self-initiated communication emissions, g) the description and comparison of communication validity between requesting and describing communication functions, h) the study of the correspondence between individualized program objectives and procedural implementation, and i) the field testing of a comprehensive continuum of training from inservice to longitudinal on-site technical assistance.

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GROUP III: COMMUNITY LIVING - OVERALL GROUP SUMMARY

FIGURE II (Cont'd)

AGENCY	PRINCIPAL INVESTIGATOR(S)	TITLE OF RESEARCH OR TRAINING PROJECT	SUMMARY/FOCUS
University of Minnesota Research and Training Center on Community Living	Stuart J. Schleien, Ph.D.	Social Integration through Leisure/Recreation Interventions.	Identify and document the best/innovative practices in developing and maintaining recreation and leisure community services and/or programs.
University of Minnesota Research and Training Center on Community Living	David Braddock, Ph.D. Richard Hemp, M.A. (University of Illinois-Chicago)	Creative Financing of Community Services	Complete two surveys on long-term financing of community services in order to address: 1) the state agency perspective, and 2) the perspective of community-based service providers.
University of Minnesota Research and Training Center on Community Living	Steven J. Taylor, Ph.D.	Exemplary Community Living Services to Persons with Mental Retardation	Identify, document, and evaluate best practices and innovative strategies related to ensuring options and supports for living in community settings. The research program also includes a detailed qualitative study of social relationships of persons with developmental disabilities in community settings.

GROUP IV: COMMUNITY LIVING II
OVERALL GROUP SUMMARY

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CENTER ON DEAFNESS, SAN FRANCISCO, CA

Two projects focused on social aspects of deaf students. One study is an investigation of social, linguistic, cognitive, and academic success among high school students with severe or profound hearing loss. Interviews with students included information on levels of social cognition, relationships, schooling, upbringing, perceptions of success, and future plans. Another study is meant to raise the social functioning of deaf adolescents and adults through structured activities and opportunities.

Two research studies relate to a testing instrument and assessment approach. One study will assess the effects of training sign language interpreters in Rorschach testing on Rorschach scores of deaf clients. The Center will also develop an approach to neuropsychological assessment of deaf psychiatric patients to discern organicity from functional disorders. Instruments and procedures will be identified to determine the most powerful in differential diagnosis among the deaf population.

The issue of linguistics is studied by investigating whether and how linguistic indicators of disordered thinking are represented in the sign language of deaf psychotics and other linguistic phenomena.

Support systems and strategies for deaf individuals are addressed in four studies. Effects of the DeafCAN program will be evaluated through the social, psychological, and academic development of students. In another study, information was obtained from eight peer counseling programs for the Deaf in California and were evaluated in comparison with other counseling programs for the deaf. One project helped to prepare deaf clients presenting for psychotherapeutic intervention through videotape material and information. A nationwide study will provide a picture of the deaf clinical population being provided mental health services along with information of their diagnostic categories.

BOSTON UNIVERSITY, CENTER ON PSYCHIATRIC REHABILITATION, BOSTON, MA

One project investigates the efficacy of early intervention of computerized language therapy for global aphasic stroke patients. This project is meant to stimulate residual abilities underlying language by providing language-like activities capable of engaging the aphasic person.

In another study, benefits of training will be evaluated for a computerized, visual alternative communication system (VIC) for chronic global aphasic patients.

YESHIVA UNIVERSITY, ALBERT EINSTEIN COLLEGE OF MEDICINE, REHABILITATION RESEARCH AND TRAINING CENTER FOR PERSONS WITH PSYCHIATRIC DISABILITIES, NEW YORK, NY

Two studies were based on vocational rehabilitation. One study was a vocational needs assessment of psychiatrically disabled individuals and was conducted using the RSA-300 Database, the findings of which has implications for policy and planning efforts. In one project, predictors were identified of successful social and vocational rehabilitation in persons with schizophrenia hospitalized at the Bronx Psychiatric Center.

Two studies address evaluation or assessment procedures. One study focuses on assessment procedures for disability determination for persons with neuropsychiatric conditions. In another study, the purpose was to assess the level of functional disability associated with tardive dyskinesia, an abnormal movement disorder.

Four projects addressed social systems and settings. One study was based on a pilot study which examined the competency of criminal defendants to stand trial and related patterns of living. In another study, the effectiveness of case management for two groups was assessed - one received assertive outreach case management, while the other received routine service. One project tested the hypothesis that family support can make a difference in the rehabilitation of clients with schizophrenia. Effectiveness of peer-group intervention was evaluated in yet another study for the transition from hospital to community living.

CINCINNATI CENTER FOR DEVELOPMENTAL DISORDERS, RRTC CONSORTIUM ON AGING AND DEVELOPMENTAL DISABILITIES, CINCINNATI, OH

Two projects will address policy issues of older persons with mental retardation and developmental disabilities. One project will identify factors fostering exemplary service delivery through an analysis of progressive states' policies and funding strategies. A second project will assess the number, type, and characteristics of community-based services available and currently used by older persons with developmental disabilities.

Projects which address social and support systems include:

- o Development and evaluation of interagency models for long-term fiscal support of small scale living options for older persons with DD;
- o Examination of major concerns of families and residents undergoing transitions of residence;
- o Nature and effects of transition like retirement for older persons with mental retardation or DD;
- o Evaluation of training intervention for caregivers to develop problem-solving skills.

Three studies will generate new information about older adults with disabilities or will disseminate current information. A longitudinal study will examine the decline in aging and aged adults with mental retardation; especially Down's Syndrome. One project will develop and adapt an assessment and intervention protocol to enable families and other caregivers to detect behavioral/functional decline in older persons with DD and intercede to maintain maximum functional ability. Finally, a third project in this category will implement an approach to expand and disseminate information about the older person with mental retardation and DD as a strategy for networking of services.

BOSTON UNIVERSITY, SARGENT COLLEGE OF ALLIED HEALTH PROFESSIONS, CENTER FOR PSYCHIATRIC REHABILITATION, BOSTON, MA

The project serves to evaluate and monitor the effectiveness of a supervised exercise and follow-up program for young adults with severe psychiatric disabilities.

THRESHOLDS RESEARCH INSTITUTE, CHICAGO, IL

Vocational rehabilitation and related service delivery describes three studies. One study is an examination of vocational outcomes among the psychiatrically disabled. Another study examines employer attitudes and hiring practices of mentally ill individuals in finding jobs outside of a rehabilitation center or sheltered workplace. The purpose of another study is to assess the relative effectiveness of supported employment versus transitional employment services for persons with severe mental illness and the cost effectiveness of the two models. The purpose of a third study is to compare the efficacy of a transitional employment of program and a

supported employment program for persons with severe and persistent mental illness. Other studies include the following:

Testing and Assessment:

- This study is an assessment which assesses the readiness of persons with mental illness to be gainfully employed within the community.

Medical Intervention:

- The medical intervention of persons with schizophrenia
- The investigation of the efficacy of Serum Fluphenazine in the medication management of schizophrenic individuals.

Consumer Based Issues:

- The investigation of the effectiveness of indigenous, veteran mental health consumers as providers of emergency assessment, linkage, and residential rehabilitation.

Family and Community Support:

- The examination of changes that occur in family members as a result of their participation in support groups, as well as the examination of the structure and processes of these groups and their leaders in order to obtain an understanding of the changes in group participants.

THRESHOLDS RESEARCH INSTITUTE, CHICAGO, IL

Family and Community Support:

- A comparison of the degree of burden experienced by parents of severely mentally ill offspring with the degree of burden reported by a group of parents of same-aged offspring who are not mentally ill and who reside in the same geographic and socio-economic neighborhood of Chicago.

Substance Abuse:

- The investigation of the broad services implications of dual diagnostic cases by comparing longitudinal utilization and outcome patterns during the rehabilitation for seriously mentally ill with and without co-morbid substance abuse.

Training:

- o This study, in collaboration with the Alliance for the Mentally Ill, explores strategies for the recruitment of Hispanic and Afro-American families by facilitating outreach to these communities.

- o Developing a training curriculum for state VR counselors in psychiatric rehabilitation and evaluate its effect on both Illinois Department of Rehabilitation Services counselors as well as their mentally ill clientele.

NEW ENGLAND MEDICAL CENTER HOSPITALS, DEPARTMENT OF REHABILITATION MEDICINE, CENTER FOR PSYCHIATRIC REHABILITATION, BOSTON, MA

Consumer issues are the target of three studies. In one study, the goal is to develop and evaluate model approaches to train consumers to administer programs, to represent their interests in program development, and to address system changes. The purpose of the second study is to develop and test technical assistance approaches to instituting client driven organizational change. Finally, an annotated list of resources which focuses on coping strategies is being developed and will be followed by a manual to be used in training. Other studies include the following:

Case Management:

- o The identification and description of major characteristics of case management models and program environments in existing case management programs.

- o The evaluation of the impact of a model case management approach on client outcomes in various case management programs.

Consumer Involvement:

- o The development of a methodology to evaluate self-help groups operated by form mental patients and mental health consumers.

- o The evaluation of the impact of rehabilitation goal-setting technology on types of goals set, consumer and staff attitudes, and consumer satisfaction with treatment.

Transition-age:

- The examination of experiences and problems confronting young adults who are completing their special education programs.

- A joint project with the Florida RTC will describe the current state of the practice of transitional programs and will conceptualize a developmental model for young adults.

- A description of the characteristics, correlates, and predictors of outcome among young adults with a psychiatric disability.

NEW ENGLAND MEDICAL CENTER HOSPITALS, DEPARTMENT OF REHABILITATION MEDICINE, CENTER FOR PSYCHIATRIC REHABILITATION, BOSTON, MA

Community Awareness and Resources:

- To create an awareness of the need for post-secondary education for young adults with psychiatric disabilities, to develop a range of programs models,
and to form a partnership with the National Alliance for the Mentally Ill.

NORTHERN ARIZONA UNIVERSITY, AMERICAN INDIAN RESEARCH AND TRAINING CENTER, FLAGSTAFF, AZ

Two projects focus on job development for American Indians with disabilities. One project resulted in the completion of a labor market study on the Navajo Nation which includes a survey of employers and their attitudes on hiring persons with disabilities. Another project will result in the development of strategies and resources in hiring persons with disabilities in Indian Health Service. Other studies include the following:

Culturally Sensitive Rehabilitation Strategies:

- The examination of the extent to which relocation of American Indians to an urban area impacts on the successful outcome of vocational rehabilitation.

- The investigation of the use of Genograms and Eco-maps to assess American Indian families who have a member with a disability.

- The assessment of the communication skills need for job interviews to facilitate the training of prospective American Indian employees of fast food service restaurants.

- A survey was conducted to assess the training and technical assistance needs for American Indian Vocational Rehabilitation Projects.

- A future project will examine the influence of sex and culture on rehabilitation service delivery to American Indians with disabilities.

Community Systems Analyses:

- A study was conducted on the needs of American Indians with disabilities. Beginning in November 1990, the study will be replicated in Minneapolis, once again, involving the participation of Indian people in the conduct of the study.

Specific Types of Disabilities:

- A national study conducted by NAU and U of A which focused on the vocational readiness of American Indian learning disabled adolescents. A follow-up study will examine tribal college accommodations for students with learning disabilities.

GROUP V: VOCATIONAL REHABILITATION
OVERALL GROUP SUMMARY

The breadth of topics being investigated is apparent from the titles listed. Examination of the summaries shows emphasis, first and foremost, on employment. In relation to employment, the topics range from early planning and counseling to rehabilitation outcomes and placement. Improved service provision to enhance rehabilitation and vocational outcomes is involved in many of the projects. This improved service provision includes investigation of transition environments, education of counselors, examination of organizational facilitators, and transformative uses of information technology. The one-page project summaries submitted include research on the focal areas listed below:

1. Consumer Involvement in Information System Planning and Use

2. Developing a Linkage for Enhancing the Accessibility and Utilization of Disability Databases

3. An Organizational Analysis Including Structure, Function, Staffing, and System Design for Information Use and Management in Rehabilitation

4. Analysis of Barriers (or Facilitators) to Information Access, Process, Use, and Management within Rehabilitation Agencies

5. The Evaluation and Development of a Software System for Functional Assessment in the Rehabilitation Program

6. The Evaluation and Development of Service Planning and Case Management Systems

7. The Review and Development of Software Systems for Evaluating Rehabilitation Process and Outcomes

8. Automated Systems to Integrate Data for Use by Rehabilitation Agencies and Disability Determination Units

9. The Development and Evaluation of Ethics Curricula for Rehabilitation Education

10. Needs and Priorities for Improving Interpreting Services in the Federal/State VR Program

11. RSA-Interpreter Training Program Data

12. Employer Development for Deaf Clients

13. Interpersonal Problem Solving for Deaf Consumers

14. Deaf Work and Rehabilitation Perceptions

15. Model Independent Living Skills Training Curricula for Deaf Consumers

16. The Career Development Experiences and Career Decisions of Deaf High School Seniors

17. Social Transition of Deaf Seniors

18. Transition of Deaf Individuals from Training to Work

19. National Study of Transition from School to Work for Deaf Youth

20. Testing an Innovative Placement and Career Enhancement Vocational Rehabilitation Program

21. Using Employer Supports to Enhance Supported Employment Outcomes

22. Career and Rehabilitation Planning

23. Assessment for Personal Choice

24. Transition from School to Work

25. Return to Work

26. Peer Support and Employment

27. Independent Living Program-Based Employment Interventions

28. National Agenda for the Employment of People with Disabilities

GROUP VI: SUPPORTIVE EMPLOYMENT AND TRAUMATIC BRAIN INJURY OVERALL GROUP SUMMARY

Abstracts from eight projects were reviewed as part of this summary review process. Only two of the projects reviewed were not affiliated with university programs. The majority of the projects had previous experience in both traumatic brain injury as well as supported employment programs, therefore most projects represented an extension of existing programs. The project summaries suggested that a wide range of issues were under investigation. These issues will be briefly reviewed in the following paragraphs. Each of the categories below represents aspects of research being conducted within these eight centers, many of which are being conducted by several centers simultaneously.

Survey Research:

The surveys that were being conducted were assessing the consumer's perspective on satisfaction and program needs, professional's opinions regarding important researchable issues and variables to consider in planning programs. Vocational outcome and social integration was a common type of survey research mentioned in the summaries resulting from previously provided vocational rehabilitation services.

Assessment Tools:

Assessment tools were being investigated in several of the projects as a primary focus of research and data collection. These assessment tools included behavioral rating instruments, instruments to measure community integration and job satisfaction, degree of productivity and benefit cost related issues.

Service Delivery Systems and Models:

Service delivery systems and models were the most frequently cited aspects being investigated by the research projects. Within this category, approaches to supported employment, transitional employment, and methods of maintaining persons in independent competitive employment with periodic case management were cited. Some critical points being examined included determination of initial points of referral, methods of providing services, approaches to using professional and lay staff in program development and ways of developing programs and services in areas where they have not previously existed. Some of the program models involved use of existing resources such as those available through university hospitals, state vocational rehabilitation agencies and private rehabilitation facilities. At least one other program examined a rural approach to

providing supported employment related services in areas in which resources were limited. The majority of the projects intend to describe the models that they have developed and tested through the model demonstration projects through the media of journal articles, book chapters, or final project reports.

Case Study Approaches:

Case study approaches describing methods of providing vocational rehabilitation services were included in a number of the project summaries. This approach involves the examination of cases in which persons with a traumatic brain injury are assessed, involved in appropriate rehabilitation programs and integrated into community-based living and employment situations.

Service Approaches:

Service approaches including methods of providing employment related services was a significant focus of the majority of the projects reviewed. The need for transitional employment as opposed to supported employment was stressed in a number of projects, and a few of the projects discussed the need for other types of employment options. Approaches using employers and co-workers to provide follow-along services was discussed in some of the project summaries. The need for developing methods of case management and intermittent work related intervention was also discussed in some of the projects.

Suggested Practices:

Suggested practices to follow in supported employment and other types of community-based work options was implied as some of the intended outcomes of several research projects. These will include descriptions of methods for involving the professional rehabilitation specialist in planning, assessment and treatment, as well as in the provision of community-based support systems and networks. Few of the projects identified the development of suggested practices with the exception of two projects which were preparing texts on community-based employment.

Job Maintenance Methods:

Job maintenance methods are being investigated which include approaches to using job coaches, employers, as well as family members and significant others in the person's life as methods of providing support. A number of the principal investigators noted the importance of not only providing initial services but the necessity of

providing ongoing maintenance and emergency or crisis intervention services as the need arises following a community employment placement. These services are apparently being provided by degreed professionals, volunteers, peer support providers from state vocational rehabilitation agencies and private rehabilitation facilities.

Issues in Community Integration:

Issues in community integration are important topics being considered in most projects. These issues include the degree of integration at work, independent living, and social environments. The quality of the integration, the opportunity for integration, and ways of assessing these phenomena are currently under investigation.

Methods of Changing and Shaping Behaviors:

Methods of changing and shaping behaviors and developing remedial behavioral strategies were repeatedly mentioned as an important focus of research. Behavioral problems are identified as a primary reason why persons with a TBI have difficulty in maintaining competitive employment and integrated community living accommodations. This issue is of primary importance from both the perspective of the subtle psycho-social interactions and behavioral changes following traumatic brain injury, as well as major personality changes and disturbances. None of the projects reviewed, focused upon psychiatric aspects and the need for psychiatric intervention. However, none of the projects reviewed specifically described these factors as independent variables.

Support Needs:

Support needs were repeatedly discussed in the project summaries as important considerations in this line of research. These supports included funding for initial services as well as a grave concern for the availability of long-term funding. In some cases, the project overviews commented on the expense of neurobehavioral rehabilitation and acute medical intervention. However, the cost of providing long-term supports and the difficulty in finding appropriate funding agents to financial long-term services appears to be an even greater issue.

Dissemination of Information:

A final area of importance included dissemination of information. There were reports of research findings being disseminated in multimedia types of productions including audio and videotapes, papers presented at conferences, articles in journals and book chapters, and texts written on the topic. All of the research projects will provide a summary of findings in the form of a research

monograph or research report.

Continuation of the Programs Started Under this Initiative

Some of the projects have also identified the availability of resources to continue the programs that were started under this initiative, and a number of researchers have investigated the possibility of additional grant funding to further develop the research initiated under these priorities. Clearly, the body of knowledge and available information in supported employment and traumatic brain injury has been tremendously enhanced by the projects sponsored by federal initiatives.

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APPENDIX C

AN OVERVIEW OF THE REHABILITATION SERVICES ADMINISTRATION PROGRAM

Mark Shoob
Associate Commissioner

OVERVIEW OF THE REHABILITATION SERVICES ADMINISTRATION PROGRAM

I was asked to talk about what we do in the Rehabilitation Services Administration (RSA), and to describe our programs. I was also told that many of you are very knowledgeable of RSA programs and that others have had limited exposure to these programs, With that in mind, I will try to be informative without boring those who are familiar with the programs.

RSA is the Federal agency responsible for implementing much of the Rehabilitation Act of 1973 and its amendments. We do this in a variety of ways, including both formula and discretionary grant programs which are administered through our headquarters and 10 federal regional offices.

The major program which our agency implements is the State/Federal Vocational Rehabilitation (VR) Program. The State/Federal Rehabilitation Program involves 80% federal money with a 20% state match. This partnership of RSA and the 83 State Vocational Rehabilitation agencies serves well over 900,000 eligible persons a year.

The VR program has the following key points:

- o It is an eligibility - non-entitlement program;
- o The criteria for eligibility are:
  - i. the presence of a physical or mental disability;
  - ii. a substantial handicap to employment; and
  - iii. a reasonable expectation of an employment outcome.

The 3-year state plan submitted by state VR agencies is an agreement with RSA which provides assurances and describes the nature and scope of the program and services to be rendered. Key points in the program include the following:

1. The state determines eligibility.
2. The Individual Written Rehabilitation Plan (IWRP) is developed together by the individual being served and the rehabilitation counselor. The plan includes both intermediate and long range goals.
3. The state agency provides or purchases the services in order to attain the agreed upon goal(s).

4. The average client takes about 2 years to complete the rehabilitation process.

5. Approximately two-thirds of the individuals served have severe disabilities.

6. Of the 900,000 individuals served annually, almost two-thirds of those accepted will be successfully rehabilitated, with over 80% going into competitive employment.

The Supported Employment Formula Grants Program is supplemental to the Basic State Grant Program which is described above. It is a competitive employment program operated by state VR agencies. The Supported Employment Program is designed to facilitate the employment of persons with severe disabilities. These individuals need on-going, extended support.

Those individuals whose disabilities are so severe that a vocational outcome is not a viable option may be eligible for Independent Living (IL) services. IL services are designed to assist the individual to live more independently in the home and community. RSA administers 3 IL grant programs as follows:

1. IL, Part A is a formula grant to state VR agencies. It is intended to lead toward a state-wide program of Independent Living Rehabilitation Services.

2. IL, Part B or Centers for Independent Living Program is a discretionary grant program that is presently funding approximately 200 IL centers throughout the country. These are consumer run programs.

3. The IL, Part C program is a discretionary grant program for older individuals who are blind. The funds go to state VR agencies serving these persons.

RSA also administers a variety of discretionary grant programs which are designed to test and demonstrate service delivery systems and innovative approaches. Such projects provide information about better ways to reach and serve the individuals who rehabilitation programs are designed to assist. RSA funds a number of special projects which focus on the needs of a wide range of severely disabled individuals, including Native Americans and migrant workers. The Projects with Industry Program brings together business, labor, and the rehabilitation community.

The Training Program for Rehabilitation Professionals provides a comprehensive program of both pre-service and in-service training. Training is funded in more than 20 disciplines. The Regional Continuing Education Programs (RCEPs) are a significant resource to state rehabilitation agencies. They have the capability of being able to quickly develop training programs in emerging areas as well as responding to the traditional training needs of the rehabilitation community.

Do the components of the RSA program all come together? Yes! We have developed a strategic management plan that identifies our goals and objectives for a five-year period. Nearly everything we do fits into one of our goals. The first year of the Strategic Management Plan is our Operational Plan. The plan includes a) what we are doing, b) the activities to achieve our goals, and c) the target dates.

Last year was the first year of this activity and I can report that we had great success and achieved most of the objectives that we had spelled out in the plan. Managers know what is expected of them and their unit. One of the major expectations is an integrated organization so that such things as discretionary grant priorities reflect the needs of the program. When we monitor programs, we use the same yardstick throughout the country.

We are implementing the Rehabilitation Act in a responsible way which assures that the program is responsive to the needs of the people it is intended to serve. The goal of working more closely with the Office of Special Education Programs (OSEP) and the National Institute on Disability and Rehabilitation Research (NIDRR) is included throughout our operational plan. NIDRR's resources and its ability to fund and to bring together a diverse group of well known and respected researchers reinforce our appreciation for the positive impact that can be brought to bear on the needs of people with disabilities. RSA is pleased to be a part of this workshop.

As a result of rehabilitation research, we have seen improvements in many areas of rehabilitation, including: medical, behavioral, vocational, management, and outreach to under- and un-served populations. We look forward to working with you and together doing an even better job of helping individuals with disabilities move from dependence to independence.

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